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ABSTRACT

The booklet, written by a parent and psychiatrist, provides basic information on autistic children and their families. Introductory sections touch on the history of the condition, its incidence, and its associated learning problems. Subsequent sections address the following topics: signs and symptoms, basic handicaps, behavior problems (such as resistance to change and lack of ability to play), differential diagnosis, causes, parents' problems, solutions (education, operant conditioning), and the role of the National Society for Autistic Children, Inc. (CL)

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CHILDREN APART

Autistic children and their families

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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

By LORNA WING, M.D., D.P.M.

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A Publication of NSAC,
The National Society for Children and Adults with Autism

Foreword

Autism is one of the most distressing of all handicapping conditions, not only because it is a life-long neurological disability which has defied all efforts to find a medical cure or cures, but also because the very complexity of autism itself tends to maintain a state of confusion among parents and professionals alike.

This book, first published in Great Britain in the 1960s, is perhaps the single most influencial document ever printed in an effort to clear away some of that confusion and offer hope to the parents of children and adults with autism; by viewing them not as part of the problem, but as active agents for positive change in the lives of the children, young people and adults who struggle with this disability.

It is written by a parent — who is also a celebrated professional — Lorna Wing, M.D., D.P.M., a noted psychiatrist, scientific investigator and activist for autistic children and their families; known for her accomplishments not only in her native country, but throughout the world.

There is hardly a parent of an autistic child who has not been given encouragement by this booklet, or a professional paper on autism which does not carry a reference to the works of Dr. Wing.

As a founder of the National Society for Autistic Children in Great Britain, Dr. Wing essentially began the world-wide movement to save these children from custodial institutions and bring them to the attention of scientific investigators and providers of service — educational, vocational and residential — whose subsequent work and dedication today offer hope where once there was none.

The original British version of *Children Apart* has been read widely throughout the world. In response to its great popularity in the United States, NSAC, the National Society for Children and Adults with Autism, has revised the original, with Dr. Wing's permission, for use by readers in the United States. Some of the British spelling and grammar have been changed, and some information pertinent to the United States has been added.

But we have left intact Dr. Wing's impeccable work, with all it's warmth and insight, so the readers in the 1980s will be charged with the same hope and will be given the same clear knowledge that perseverance, based on common sense, intelligent action and sensitivity can bring dignity and purpose to the lives of those with autism and their families.

Our appreciation is extended to Dr. Wing for her gracious cooperation in this project, to the British National Association for Mental Health for their permission to reproduce *Children Apart*, to Dorothy Miller who first edited the U. S. version in 1974, to the American Legion Child Welfare Fund which provided means for dissemination of the publication to parents across the country and especially to Harmony, Inc., an international organization of singers which has adopted NASC as their focus for charitable giving and which has provided funds for this 1982 edition.

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September 1974
National Society for
Autistic Children

Autistic children and their families

Until the early 1960s very few people who were not doctors, psychologists or teachers had heard of autistic children. Recently, however, the problems of these children have been discussed in newspapers and magazines, and most people know that autistic children exist, even if they have only a very vague idea what the children are like.

This new interest may have given the impression that autism is a new problem. In fact, it is possible to find descriptions of children who were clearly autistic, in books and papers written long ago. One of the most interesting is an account called *The Wild Boy of Aveyron* by a French physician, J. M. G. Itard, first published in 1799. Itard was given charge of a twelve-year-old boy who had been found wandering in the woods of Aveyron. His description of Victor's behavior, and of the special teaching methods he devised, make a most interesting and moving story. Itard's ideas on education are still used in teaching handicapped children to this day.

Children suffering from autism, however, were only recently identified as a separate group. In 1943 an American child psychiatrist, Leo Kanner, first described the syndrome of *Early Infantile Autism*. The word autism comes from the Greek word *autos*, which means *self*. Kanner used this name because the children go through a stage when they seem very withdrawn into themselves and do not show much interest in other people. However, many of them are like this only when they are very young (under five or six years old) so the name is not really a very good one.

Even after Kanner described and named the children, it was almost twenty years before the general public began to hear of them. Nowadays, there is much more widespread interest, partly because attitudes to all kinds of handicaps have changed and people are willing to talk about these problems and do what they can to help, and partly because a group of parents and professional workers started a society to help autistic children.

I hope that this booklet will be of some interest to readers who are not working or living with an autistic child, as well as to those who are directly involved as parents or teachers. It is true that autism is a rare condition compared with, for example, Down's syndrome (the correct name for mongolism), but it is still common enough for most people to know at least one autistic child, perhaps as a neighbor, perhaps as a relative, or a child of a friend. I shall describe how the children behave, and how this behavior affects their families, give an account of the recent ideas about why they are so different from normal children, and make some suggestions as to how friends, neighbors and relatives can help.

How Many People Have Autism?

Using Leo Kanner's criteria, studies made in England, Denmark and the United States show that about five in every 10,000 children will have autism. Children who have many of the symptoms of Kanner Syndrome, or "classic" autism, but not all of them, form a group that is roughly twice the size of the Kanner Syndrome group. Thus, for educational and other service delivery planning, the incidence figure is about 15 in every 10,000. This is the figure used by the National Society; and it means that in the United States there are about 340,000 persons who are "autistic." About 113,000 are children aged 21 and below, and 226,000 are adults.

Early studies seemed to indicate that parents of autistic children tended to have a higher educational or occupational level than average, but this is no longer thought to be true. Autism occurs in all parts of the world, in families of all races, backgrounds and socioeconomic conditions.

Boys are affected three or four times more often than girls. No one knows why this is, but most conditions in which language problems are important seem to be more common in boys.

The condition begins at birth. Children can develop other kinds of abnormal behavior after this age, but it is most unusual for the typical autistic symptoms to begin after three.

Roughly one third to one half of the children who have autistic behavior also have some other severe condition affecting the central nervous system, such as epilepsy. The rest appear physically healthy apart from their strange behavior, although special examination often shows that they have difficulties which may be due to some abnormality in the brain.

There seem to be autistic children in all parts of the world, although it is not yet possible to say what differences there are in the numbers in various countries.

Learning problems

Autistic children seem very strange and puzzling to people who know nothing about them, but they are easier to understand if they are looked at as a group of children with severe learning difficulties.

Special learning problems are very common even in children whose intelligence is otherwise quite normal. Some children have great trouble in learning to read, because they find it difficult to distinguish right from left, tend to write backwards, and cannot tell the difference between letters such as b and d, p and q, w and m. Some are very slow with arithmetic, and others may have problems with hand-eye co-ordination, so that their handwriting is poor and they cannot do handwork or play games well. However, if a child has one learning problem only, and if it is not too severe, he can usually overcome it well enough to make progress at school, especially with the help of a good teacher.

Autistic children are unfortunate in that they have several severe learning problems at once, including some which hinder the development of one of the most important human skills — that is, the ability to understand and to use language. When they are young, it seems that they cannot make sense of the things they see and the things they hear. Their eyes and ears are usually quite normal and so are the nerves which take the messages from the eyes and ears to the brain. The problem seems to arise at some stage during the process of ***interpreting*** these messages. It seems that information from the outside world is not made into a clear and understandable picture, but remains a confusing and frightening muddle. An autistic child must feel like a normal person would if he were left alone in a foreign country without knowing the language or customs, or being able to read the alphabet or even understand the gestures which people made.

A normal person in this situation could begin learning the language, but the autistic child does not seem able to do this. It is hard to imagine that someone could hear words and see gestures clearly but not understand them. It makes it a little clearer if you think of people who are tone-deaf to music. They can hear all the sounds, but the most beautiful symphony has no more "meaning" to them than water running down a drain. You could say that autistic children, are in a way, "tone deaf" to any kind of language.

No one knows exactly at which stage of "information processing" the difficulties occur. Some people working with these children feel that the information from the senses is distorted in some way, thus making it difficult for the child to understand. Others feel that the information is received normally but that the problem lies in the child's difficulty in understanding the meaning of *symbols*. For example, an autistic child may, unlike some other retarded children, be able to copy a picture of a triangle at the normal age, and match triangle shapes and so on, but he takes a very long time to learn that the word "triangle" is a symbol for the shape. Even after he has learned to name many different things, he will still have difficulty in linking words together into sentences. He has even more trouble in understanding the connections between things, and therefore in working out answers to questions like "Why did so-and-so happen?" "What is such-and-such for?" "How is this done?" "What is the reason for that?" The abstract ideas and complicated meanings of words in poetry and literature are completely beyond these children even if they eventually learn to read fluently.

Research workers are investigating these problems, and trying to devise tests to define exactly where and when the children's difficulties in understanding begin. Many problems are still unsolved, but it is possible to describe how an autistic child behaves, and how he can be helped.

First signs and symptoms

If a child is autistic from birth, it may be quite difficult in the first few months for an outsider to guess that there is anything wrong. Sometimes a mother has an uneasy feeling that her baby is unusual in some way, but is unable to put her finger on what is wrong. Perhaps the reason is that an autistic baby does not show all the little signs of awareness of his mother's presence which the normal baby does from an early age.

Some autistic children are "model" babies, hardly ever crying even when they are hungry. Others behave in exactly the opposite way. They scream continually and cannot be comforted except perhaps by continual rocking or by riding in a car. In this case even short stops for traffic lights will cause the screaming to begin again. Both kinds of babies are difficult and unrewarding for the parents, the quiet ones because of their lack of responsiveness, and the over-active ones because of demands which can never be satisfied. Neither the quiet nor the over-active babies lift up their arms or make themselves ready to be picked up when their mothers come to them. This is quite unlike normal babies who, when they are strong enough, show just how eager they are to be picked up and cuddled.

Feeding problems are fairly common, beginning with poor sucking after birth, and sometimes going on to a refusal to chew any lumpy food when the child has been weaned.

Many of the children smile and sit up, crawl and walk at the usual ages, but they may smile only when rocked, bounced or tickled, and they often do not bother to sit up and look at the world around them even when they are able to do so. They do not point things out to their parents or show any of the normal baby's delighted interest in the world. They may not even reach out for their food when it is placed in front of them.

Sometimes these children spend hours scratching on the covers of their baby buggies. This behavior also occurs in babies who are blind. When they reach the age at which a normal baby can handle toys, they seem to be interested only in the feel of the surface of the toy, and the way it looks when it is twisted and turned, instead of trying out all its possible uses as a plaything. They may be fascinated by lights, and will often stare fixedly at a lighted lamp, perhaps smiling and chuckling and wriggling with excitement.

The toddler stage

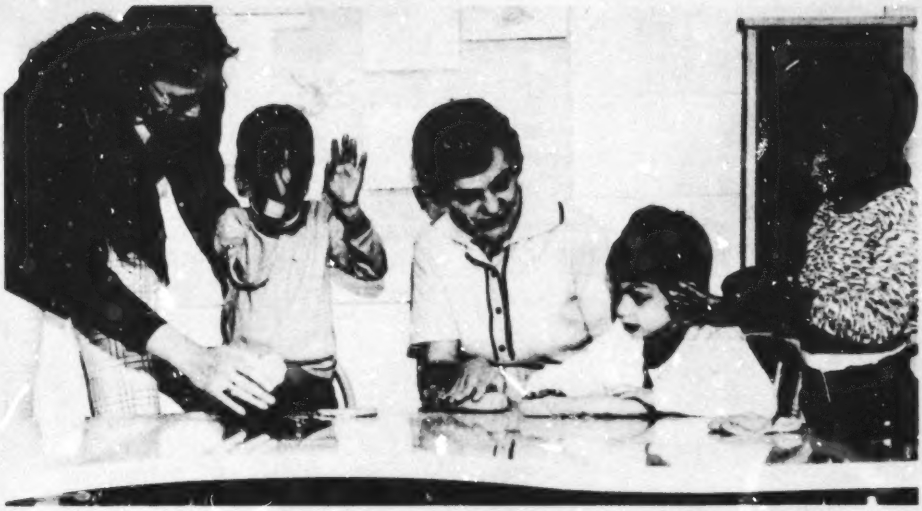
Even if the parents have not worried about their child in his baby stage, when he reaches his second year the problems become obvious. This is partly because he does not begin to talk at the expected time, and partly because it is much easier to notice unusual behavior in a child who is mobile than one who is lying in a crib. Furthermore, at this stage the child himself begins to be frustrated by his handicaps and reacts to this in various ways depending on his temperament.

Unusual response to sounds

An autistic child in the toddler stage seems to respond to sounds in quite unpredictable ways. He may completely ignore some very loud noises, but at other times cower away from a sound, covering his ears as if in distress. Yet again, the same child may be fascinated by a special noise, such as that made by a friction-drive toy. What is really upsetting, however, is that he often shows no interest when people talk to him, not even when they call his name.

Lack of understanding of speech

The children are uninterested in speech because they do not understand its meaning. At first it seems to the bewildered parents that their child is quite deliberately "shutting his ears" and refusing to listen. However, when the children grow older, they do begin to try to understand, and it is then possible to see how much real difficulty they have. Those who make progress go through a stage in which they can understand and willingly obey very simple instructions, but are still muddled by anything complicated. One little boy learned the meaning of "give me the cup" but he could not understand when his mother said "put the cup on the table." At this stage it is clear that the trouble is not due to lack of co-operation. The children may have the same reaction as an Englishman who knows just a little French, when he is with French-speaking people. He will understand the simple familiar sentences, but when the conversation gets at all complicated, he will stop listening. Like the autistic child, his attention is not on the conversation, but, also like the autistic child, he has a genuine "handicap" which makes it very frustrating for him when he tries to listen. Most of us lose interest when we are asked to do something well-nigh impossible.



Picture Courtesy of Vista Hill Foundation

The basic handicaps

Late talking and speech difficulties

Autistic children are always late in learning to talk and some never talk at all. In the early years the only means of communication they have is to scream until someone finds out what it is that they want. At a slightly more advanced level, they will grab an adult by the hand and lead him to the desired object. The majority eventually learn to use at least some words, but their speech is clearly abnormal.

When they first begin to talk they usually repeat the words that other people say. Sometimes the first word a child uses is the one which ends a nursery rhyme his mother has sung to him many times. As well as repeating a word just spoken, autistic children tend to echo words, phrases or sentences they have heard other people use in the past, perhaps weeks or months earlier. They may copy the exact accent of the speaker, even that of a foreigner. If the opportunity is present, a child may "pick up" phrases or whole sentences using different foreign accents. These echoed sentences may give the impression that the child is talking with understanding, especially if they are used at an appropriate moment (as with the child who always said "pick it up" if someone dropped something) but anyone who really knows the child will realize that the words are meaningless copies.

The next stage comes when the child begins to use these copied phrases to obtain something he wants. For instance, he may hear his mother say "do you want a cookie?" before giving him a cookie. When the child wants a cookie he uses the same words as his mother. This means he refers to himself as "you" or by his name, instead of "I." This is called "reversal of pronouns" and is very characteristic of autistic children.

The next step forward is when the child produces some sentences which he has made up for himself. Whereas the copied phrases seemed to be said quite easily, an autistic child usually has to make a long painful effort before putting a few words together, and the sounds seem to be forced out with considerable difficulty. Sometimes the first real sentence comes out under the stress of great emotion, as for instance when a small boy did not want to be left with a babysitter, and said, to the astonishment of everyone, "Mommy-not-*going* out." Very often the child has trouble in arranging the words in the right order, and may say "table sit-up" (instead of "sit up at the table") or "take park to doggie." He is not able to comprehend the difference.

The little words in sentences cause endless trouble just as for a normal person learning a foreign language. At first the autistic child does not use them at all, and says "dinner now," "go shop" and so on. Later he will try to use them, but make many mistakes, saying "put it from chair" instead of "on chair" or making one word do for "under," "be-

side," "on top," "through," and all the other words indicating position.

Words that often come in pairs are easily confused. Brush may be used instead of comb, sock instead of shoe, and on instead of off. The words "you" and "I" still cause problems even when the child has stopped repeating and echoing. It is in fact very difficult to explain that when I say "I," I mean *myself*, but when I say "you" I mean *yourself*, but when *you* speak it is the other way around. Perhaps the surprising thing is that normal children learn this so quickly, not that autistic children find it so difficult.

Usually each word has one meaning, and one meaning only for an autistic child. A ten-year-old autistic girl who had at last learned the meaning of the word "up" was very puzzled when asked to "walk up the aisle" when trying on shoes in a shoe store. She looked round in desperation, then saw a step-ladder and walked up that.

Even if they do learn to use grammatical constructions correctly, autistic children are still handicapped because they find abstract ideas so difficult to grasp. They do not seem to see the connection between one event and the next unless it can be shown in a very concrete and practical way. If you want to show an autistic child that the hot water from a faucet is heated by a water heater in the basement, you cannot expect him to understand if you just tell him in words; you must take him to the basement, show him the burner or heating element in the water heater, the tank, and then trace the pipes all the way back up to the bathroom faucet.

Problems of pronunciation

Although when they copy other people autistic children may speak very clearly, they usually have poor pronunciation when they produce their own phrases. They have poor control over the volume of the sound they make, and they may speak much too loudly or almost in a whisper. The pitch of the voice is often wrong, the words being all on one note, or else rising and falling in the wrong places with the emphasis on the wrong words. Sometimes the children seem to "play" with sounds, and speak in a voice quite different from their normal one. They may do this when they are unsure of the right thing to say, and also when they are imitating other people.

Problems connected with the use of vision

A young autistic child often seems to respond to the things he sees as oddly as he does to the things he hears. He may ignore things which would be of great interest to a normal child, but be fascinated by something quite trivial. Parents of these children are quite used to the situation where the child comes into a room full of people and runs straight through them as if they do not exist, because he has caught sight of a tiny piece of shiny paper on the floor in the corner. The same child may gaze entranced at a street lamp, but shrink and cover his eyes from a fairly strong light used for photography.

It is usual for these children to react to moving objects much more than to things which stand still. An autistic toddler used to like throwing pebbles in the pond in his garden. He would scream for more pebbles even though he was surrounded by them. If, however, they were rolled along the ground for him, he would see them at once, as long as they were moving, and would stop screaming and pick them up to throw.

The children tend to look through or past other people, or else look at the reflection of the light in another person's eyes. This is very disconcerting and adds to one's feelings that the children are strange and remote. However, the reason for this behavior is that the autistic child really has problems in comprehending the things he sees, and when he is very young, he is not able to grasp the idea of a whole human being, or to know that it is customary to look at people's faces. One mother described how her autistic son recognized her by her outline and not by the details. He therefore tended to follow other people who were wearing the same kinds of clothes, assuming that he was following his mother.

It is not surprising that many autistic children are not at all interested in pictures in their early years. The mother of one child found that her little girl only began to realize what pictures were all about when she was shown the real object together with the picture.

Problems with visual language

A deaf child will make up for his language problem by using gestures and miming to communicate. Autistic children cannot do this because they have as much trouble in comprehending unspoken language as with the spoken word. They often do not learn even a simple gesture such as pointing until

they are over five years old. However, understanding of this kind of language usually develops more quickly than understanding of speech, so the older autistic child tends to watch for visual cues from other people to make up for his difficulty with speech. However, few of them learn to mime, and they do not, for example, pretend to drink from a cup to show that they are thirsty. Because of their problems in understanding any kind of language, young autistic children are quite as handicapped as children who are born both deaf and blind.

Today, a few experts in the United States are teaching older mute autistic children sign language used by the deaf. This seems to be helping some of these children a great deal. It can give them a means of communicating with their environment, which can help ease their tremendous feelings of frustration at being unable to talk. In a few instances it has actually given these children the confidence they previously lacked to attempt some verbal speech.

Ways of exploring the world

Like deaf/blind children, autistic children try to make up for their handicaps by exploring the world through their senses of touch, taste and smell. They make contact with people through touch, and they seem to find endless pleasure in the feel of surfaces like smooth shiny wood, soft fur, or plastic. This may lead to problems, as in one seven-year-old who loved fur coats and tended to run up to anyone he met in the street who was wearing one, so that he could stroke the fur and rub his face against it.

Although the children seem to understand things they feel better than things they see and hear, even here there are some abnormalities in the early years. Some of the children appear not to notice pain, and may ignore bumps and bruises. They may run out without any clothes as if they do not feel the cold. This does not usually last after four or five years old, and later on the children may be very sensitive to discomfort.

Like deaf/blind children, autistic children have many odd movements. They like to jump up and down, spin round and round, walk on tiptoe, flap their arms and legs like an excited baby in a high chair, and twist and turn their hands very quickly near their eyes. It may be that both the deaf/blind and the autistic children are trying to find some form of stimulation which they can enjoy. Another possible explanation is that children with visual difficulties are very immature in their patterns of movement and carry on for years with activities which would be normal in babies and toddlers.

Difficulties with skilled movements

Many, though not all, autistic children appear to be very graceful and agile in movement. However, when attempts are made to teach them skilled movements, such as skipping, dancing, swimming, or throwing a ball, it soon becomes obvious that they have great problems. A teacher in a special school described how her children fell over their own feet and ended in a heap on the floor when she first began to teach them a folk dance. The interesting thing is that the difficulty seems to occur when the children try to copy the movements made by other people. If their own limbs are moved in the correct way by the teacher so that they feel the movements, then eventually they learn to perform very well.

Careful analysis and observation has shown that the children tend to become confused when they are asked to distinguish between left and right, up and down, back and front. In addition to mixing up the letters b and d, p and q, m and w, which some of them do, they often put their clothes on backwards, copy someone pointing up by pointing down, and set the table with the knives and forks pointing the wrong way.

Picture Courtesy of Vista Hill Foundation

Behavior problems

Social withdrawal

It is not surprising that children with these handicaps have many behavior problems. The saddest thing for parents is that their child appears to be indifferent to them in his early years. Indeed he seems to be unaware of the existence of anyone else at all. This is why some writers have used phrases like "Children in a dream world" or "The child in a glass ball" to describe these children. However, this behavior follows as a secondary consequence of the difficulties in communication. As they very slowly learn to speak and to understand language they become much more friendly and sociable — in fact some autistic children eventually become quite cheerful extroverted personalities, although their handicaps prevent the development of a really adult and mature relationship with another person. This is why the term "autism" is not really appropriate.

Resistance to change

As they live in such a confusing world, it is not surprising that autistic children try to cling to the few things which they do understand. They like to keep to the same routines and a slight change may produce screams and tantrums. They also become very attached to objects, which may be ordinary toys or such apparently uninteresting things as empty bottles, packages, leaves, or pieces of paper. Some of the children go through a phase where they carry round huge burdens consisting of their favorite things and become quite desperate if they are lost.

This dependence on routines and clinging to objects may make life very difficult for the whole family, since the child may insist on everyone else fitting in to his demands. One mother who lived in the country described how she had to lay the fire in precisely the same way and light precisely the same corner of the paper each day to prevent her child screaming for hours on end if he saw any variation whatever.

Emotional responses to situations

Another consequence of the autistic child's handicaps is that he is liable to be frightened of quite harmless things, perhaps because of one small unfortunate incident. One child put his hand into a bath that was a little too hot and refused to bath again for years. Another would not wear shoes after a new pair had rubbed his heels.

On the other hand, their lack of understanding allows the children to ignore real dangers. They may run across the road in front of traffic, or balance dangerously on narrow ledges without any fear. At times they smile and laugh at the things which give them pleasure, such as a flickering light, or the smooth feeling of something they are holding. At other times they may weep tears of deep distress — then it seems that the world is too much for them and they feel lost, bewildered and frightened. They can only be comforted by close physical contact with their mother or someone else they know and trust.

Lack of ability to play

Normal children learn through their play. They gain experience in working with things and interacting with other people. In order to play, a child needs imagination and imagination grows with the growth of language. Children who are not autistic but who cannot talk for other reasons are able to play if they have any kind of non-verbal language. Autistic children have problems with *all* language skills and they are unable to develop the usual play activities. Their only occupation, when they are young, is to hold and feel and twist and turn objects in their hands. Later on they may learn to do puzzles and build with construction toys, or to paint and draw, but even then they tend to copy and follow rules rather than to create new things.

Picture Courtesy of Vista Hill Foundation

Socially difficult behavior

Autistic children, even if they were "model" babies, are usually extremely difficult in behavior when they are between two and five years of age. They have no understanding of social requirements, so they tend to scream in the street, grab things in stores, tear up papers, tear the wallpaper, kick and bite other people and themselves, and in general act in an extremely immature way. It takes years of careful training before they learn to behave well in public and at home.

Special skills

Most parents of these children have the feeling that their child is potentially normal and intelligent, if only they could find the key to the mystery of his strange behavior. This is probably because most of the children look normal (in fact, many are physically very attractive), and also because they often do have some skills which stand out in contrast to their other difficulties. These skills are usually of the kind which do not involve *language*. For example most of the children love music and some can sing very well. They tend to be good at jig-saw puzzles and construction toys which depend on an awareness of shapes. Some are very clever with mechanical or electrical things. This is not true for all of the children — some are handicapped in almost all ways, but most are much better with activities for which words are unnecessary.

There are some rather rare autistic children who are outstandingly gifted in some way. They may be able to calculate long and intricate sums in their heads with great speed and accuracy. Some can play musical instruments or even compose tunes. A few people who were autistic children are earning their living as piano tuners because they have an unusually accurate sense of pitch. Unfortunately even these specially gifted children are often unable to manage the ordinary affairs of life and need someone in the background to organize their lives for them.

These are the children who stand out in people's memories and are almost legendary among teachers and child psychiatrists. Most autistic children are not like this. Most of them have learning problems that make them generally retarded.

Later development

Some autistic children make no progress at all, and remain mute and withdrawn all their lives. The majority, however, tend to show at least a little improvement as they grow older, especially after five or six years of age. Their basic handicaps begin to improve and the world gradually becomes more understandable to them. A number of autistic children were followed up by a research worker. A few (15 per cent) made very good progress by the time they were adolescent. Another 25 per cent did well enough to suggest that they could work in sheltered employment. The rest did not do well and most of these were placed in institutions. However, these figures were based on children who had not received any *special* help. It is to be hoped that the development of methods of education and training adapted to the needs of autistic children will enable many more to make good progress in the future.

MARION SCHULZE, Photographer

Other children have problems too

Normal children

All of the behavior I have described can be seen in young normal children as they go through various "phases." There is nothing unusual about a toddler who, for example, likes routine, who clings to his teddy bear, has temper tantrums, and sometimes ignores people who talk to him. The difference is that an autistic child does all, or almost all, of the things I have described all the time, for years on end, and does very little else at all.

Other kinds of childhood psychoses

There are various patterns of strange behavior in children which can be grouped under the general heading of "childhood psychoses." Early childhood autism is one of these patterns. It can be distinguished from the others by the early onset (before three years of age) and by the presence of the characteristics described in this booklet. The children who have autistic behavior in its most classic form are easy to identify, but some children have mixtures of different patterns, making diagnosis much more difficult. In practice, it is much more important to describe each child's specific learning problems and his educational needs than to argue about which label to give him.

Deafness

Deaf children can be very withdrawn and difficult when young and may be backward in development. Many autistic children are thought to be deaf at first, but their parents usually notice that they can tell the meaning of some soft sounds which are significant for them, such as the rustle of a candy wrapper. Very careful testing of hearing is obviously most important before making a diagnosis.

Speech problems

Children with a condition called "aphasia" also have problems in understanding spoken words, and in talking. When they are young they may go through a phase of being socially withdrawn. However, they do not have such marked difficulties with comprehending what they see as do autistic children and they can make themselves understood in non-verbal ways through gesture and miming. Again, careful observation of the child and detailed questioning of the parents is needed to make the diagnosis.

Mental subnormality

This is a very difficult problem, because of the way people use the words "subnormality" and "autism." If a child is called mentally subnormal, this means that his development is a long way behind that of normal children of his age, and also that he does very badly on the tests that psychologists use.

It is important to remember that there are hundreds of different causes of mental subnormality. Just a few examples are Down's syndrome, phenylketonuria (a condition when the body cannot deal properly with ordinary food and so the brain becomes poisoned), various illnesses in early life which damage the brain, and so on. There are also many different kinds of handicaps included under this general heading. Some children can talk fairly well but cannot learn to read or write. Some are especially clumsy and cannot learn any practical skills. Some are unable to acquire toilet training and others can never learn to walk or feed themselves.

Picture Courtesy of Vista Hill Foundation

Children are diagnosed as autistic because they have the special combination of handicaps affecting language and behavior which I have described, whatever the underlying cause, and however they perform on intelligence tests. Some of them have high scores if they are given tests which do not need a knowledge of words and language, although they will probably show up as backward on verbal tests. Others have low scores on all kinds of tests. A child can therefore be both autistic *and* mentally subnormal, or autistic but *not* subnormal in all respects, or subnormal but *not* autistic. A detailed description of each child, including his skills, his handicaps and the way he behaves is much more use than a single label. For example, a child could be described as follows: "He behaves like an autistic child, he scores very badly on vocabulary and word meaning tests, but he is only a little behind in arithmetic."

This is better than saying "he is autistic" or "he is subnormal" because these terms give only a small part of the picture. It is not surprising that parents feel annoyed if they have an autistic child and someone says "he is just subnormal and you won't admit it." On the other hand, just because a child has autistic behavior, this does not mean that his intelligence must be normal, as some parents mistakenly believe.

Surveys of groups of autistic children suggest that approximately 20 per cent obtain scores on non-verbal intelligence tests which are in the normal or above-normal range, approximately 25 per cent score in the mildly retarded range, while the rest, 55 per cent, have scores similar to those of children who are severely retarded.

What are the causes?

Although research workers are beginning to piece together the details of the handicaps from which autistic children suffer, much less is known about the basic causes.

It has been suggested by some psychiatrists that the problems are all emotional in origin; due to abnormalities in the characters of the parents, and the way they handle the child from the time he is born. This kind of theory is not very convincing. First, systematic studies of parents have not shown anything unusual in their personalities apart from the problems common to parents of handicapped children in general. They do not have severe mental illnesses any more often than other people. Second, most of these parents have other children who are quite normal. It is possible to have two autistic children in one family, but it is rare. Third, none of the excellent studies of old-fashioned institutions, where babies really were deprived of maternal care, has shown that they caused early childhood autism. The interesting and curious fact that the parents of typical autistic children tend to be above average in intelligence does not mean that they are less satisfactory as parents; probably the reverse is true. Autism may be more common in the children of brighter people for genetic reasons, rather than because of a special environment.

Most of the evidence available now points to a physical cause probably affecting the development of the parts of the brain which deal with language and with the higher organization of information coming in through the senses. In some cases there is a clear history of the onset of autistic behavior following an illness such as encephalitis (inflamation of the brain). As mentioned earlier, between one third and one half of autistic children have additional handicaps from physical illness or injury affecting the brain and central nervous system. This proportion is much too high for the association to be mere coincidence.

In those children who have no evidence of physical abnormalities on the rather limited methods of examination now available, it is possible that the problem is one of extremely slow development of the relevant parts of the brain, perhaps due to a genetic cause.

The basic handicaps shown by the children make sense in terms of brain development and function. They closely resemble those found in other conditions which have clear physical causes, such as congenital aphasia, or congenital deafness and blindness produced by German measles in the mother during pregnancy. When these facts are considered, there seems little doubt that autistic behavior is based upon physical impairment of certain aspects of brain function.

The final step in the argument is the usefulness of this "physical" theory when planning the children's education. The most successful educational programs have been based on a clear understanding of the children's handicaps, while those based on a theory of an 'emotional' cause have contributed little or nothing to progress in this field.

It is important however, to realize that emotional problems can develop as a consequence of underlying handicaps.

The relationship between a young autistic child and his mother is different from that between a normal child and his mother. The bond between a mother and her child depends upon the way the baby behaves as well as upon the affection and attention of the mother. The more the baby smiles and chuckles and wiggles with pleasure when he sees and hears his mother, the more she enjoys talking to him and cuddling him. This close contact in turn gives the baby the interest and stimulation he needs to help his physical and psychological growth. A baby who is autistic may be so quiet and unresponsive that his mother has to make a conscious effort to play with him. On the other hand, he may be irritable, difficult and demanding, but may not seem to find any comfort in contact with his parents, and they lose heart and feel that they are useless. Either way, the normal relationship of mutual enjoyment and understanding cannot develop properly. If the mother is given the right advice she can set about the task of helping her child to become interested in herself and other people, and thereby create a more normal relationship between them.

Parents' problems

Having a handicapped child, whether his problems are physical or psychological, is a heavy burden to bear. The parents may feel guilty, even though they love their child and have done their best for him. They worry about what will happen when they are no longer alive to care for him. They also have to think about the effect on his normal brothers and sisters. The situation is a major crisis for any family, and inevitably produces emotional problems.

Parents of autistic children have the same problems as parents of other kinds of handicapped children, but in addition they have some special difficulties to face. Most autistic children look quite normal and are assumed to be normal at birth. The parents live through perhaps one or two years during which it slowly becomes obvious that their child is handicapped. All this time the parents are half aware of the problem and half resisting awareness — sometimes feeling a sharp stab of anxiety when they compare their baby with a normal child, at other times reassuring themselves because he crawls and walks at the usual age and looks so bright and intelligent. This long process of doubt and indecision does nothing to ease the pain when the truth is known for sure.

Autism is not very common and most people know nothing about it, so the parents feel quite alone and in the dark about the cause of the condition and what they ought to do about it. Because the children look normal, other people often do not understand why an autistic child screams or behaves badly in public and parents receive critical frowns instead of sympathy and help. A child with very disturbed and unpredictable behavior is a much greater strain than one who is handicapped but behaves well. Sleepless nights may add to an almost intolerable burden in the early years.

The children need constant care, and it requires considerable patience and skill on the part of the parents to make sure that the normal brothers and sisters receive their fair share of attention.

You may wonder why parents struggle on with these difficult children. Most of them love their handicapped children deeply and try hard to keep them at home. Bringing up a child, however difficult, makes loving feelings grow inside most people, and parents feel that the child is part of themselves and the family and they do not want him to go away. As well as this, autistic children can be most endearing and their very helplessness and confusion brings out deep emotions in others. Then, when they start to make progress, the happiness each little step forward brings seems many times greater than that given by the rapid progress of a normal child. However, it often happens that, for many reasons, such as illness or sheer exhaustion, parents have in the end to find residential care for their child.

What can be done?

There is as yet no medical treatment for early childhood autism. Sleeplessness and overactivity can be helped by the right drugs, but there is no medicine which can help the underlying handicaps.

Psychotherapy and even psychoanalysis have been tried but most workers agree that these methods cannot help young children who have such severe language problems and difficulty in understanding the world. Where psychotherapy can help is in the case of an older adolescent autistic child who has improved enough to understand that he is different and also begins to understand some of the problems of living. He may become very depressed and anxious if he has that kind of temperament (like one boy whose mother died, and another who suddenly realized the meaning of death) and a therapist could help him through this stage.

Education

The lack of any medical treatment does not mean that nothing can be done. Although the children have severe learning problems, they can be taught by skilled teachers using special methods. In this way, they can learn, at the very least socially acceptable behavior and the basic skills of living, such as washing, dressing, using a knife and fork and so on. Some show themselves capable of far more than this and learn to read, write, do arithmetic, algebra and geometry, woodwork, metalwork, needlework and music. As is to be expected, even the brightest autistic child always has difficulty with subjects needing an understanding of words, such as English composition, literature and poetry. Many learn to read, some fairly fluently, but very few will read with much understanding or choose to read for pleasure. It seems that the children learn the mechanical side of reading and letter and word recognition, pronunciation and spelling, but this may be independent of the understanding of the meaning of the words.

Education of these children does not cure them of their handicaps and it does not make them normal. One aim of teaching is to help them to find some way around their difficulties, just as a blind child is taught to read with Braille and someone with paralyzed legs is taught to strengthen his shoulder and arm muscles. Another aim is to help the children to become acceptable members of society so that they can live with their own families. A third is to teach them the skills necessary for earning a living, in open employment if possible, or in a sheltered environment. Perhaps most important of all, the teacher tries to help the autistic child to understand more of the world, so that it is a less puzzling and frightening place and so that he can find some pleasure and enjoyment in life.

Methods of education

Teachers and parents are faced with the problem of teaching without using words. If you think of the part that written and spoken words play in the education of normal children, you will realize how difficult it is to do without them.

The very first step is to help the children to behave more normally. It is impossible to teach a restless, destructive, screaming child. He must be able to sit still quietly, at least for a short time, in order to learn anything at all. The only way to accomplish this is through a firm and consistent approach. The teacher must show the child that she wants him to sit down by placing him in his chair and keeping him there for a short time, praising him while he is there. The time can gradually be lengthened until he is quite used to sitting still. He will not understand the words, but the tone of voice helps to convey the simple meaning. It is important that he should learn that screaming, kicking, biting or destructiveness do not produce a reward, but that good behavior has enjoyable consequences. This stage can be very wearing for the teacher and parent and may seem to go on for ever, but patience, firmness and consistency produce results in the end.

The next step is to teach simple skills like buttoning up clothing or eating with a knife and fork. This is done by putting the child's limbs and fingers through the movements. At first his fingers feel quite limp, but eventually he will catch on and begin to move his hands in the right way. He may need to have his teacher touching his own hand for a long while after he is quite able to do these things, but in the end he will manage by himself. Many things can be taught this way, including throwing and catching a ball, riding a tricycle and even simple country dances.

Language training plays a big part in teaching autistic children. At first they have to learn the names of things by linking the name with the actual object. When learning the word "table" they

must see and feel a real table, and lots of different tables, otherwise they may thing that "table" refers to the light brown square object in the dining room, and not to any table of another size, shape or color. Verbs like "sitting," "walking," "running" can be acted out to show the child what these words mean. Training of this kind has to go on the whole time. Very slowly, new words, new phrases and new ideas can be taught, but the teacher must always be sure that the child can understand what he learned before she goes on to something new.

The biggest problem about teaching autistic children is their difficulty in generalizing from the things they learn. A child can be taught to button up his coat, but still not realize that the same actions are needed for the buttons on his pajamas. He may eat an orange that has been peeled, but not know how to deal with one that is cut in half. He may be able to read words written in large red letters but be puzzled by words printed smaller and in black. The world has to be built up for him, brick by brick. None of the steps can be missed out and sometimes it seems that a lifetime is not long enough for this task. However, the patient effort required does eventually produce results, even though there are often long periods when there seems to be no progress at all.

If parents are told what to do, they can begin to teach their child before he goes to school. It is very important that he should go to a special school when he is ready, because trained teachers have much more specialized knowledge than the ordinary parent. When their child goes to school, the parents can help by making sure that he has a happy home life with plenty of outings and chances to meet normal children.

What is "operant conditioning"?

There has been a lot of discussion about "operant conditioning" recently. The idea behind it is simple and has been known for a long time. It is that children (and adults too) will prefer to do things for which they are rewarded and avoid doing things which lead to unpleasant consequences. If a child is given a piece of candy whenever he screams, it is easy to see how the effect is the reverse of what is intended. If, instead, he were shown that he would be given a piece of candy only when he was quiet and well behaved, he would scream less and behave a little better.

Some psychologists have used this idea to plan a whole system of teaching. It is a useful way of helping a child to improve his behavior so that he is ready for school. Children need to be praised and rewarded for good work and also have to understand that they cannot get away with bad behavior. This applies to handicapped children quite as much as to normal children. Teachers have always known this and in this sense they all use "operant conditioning." However, experts in this field have developed certain special skills. The first is the use of good timing. With a child who cannot talk much, it is most important to show him that he has done well, or has misbehaved, *at once*. It is no good saying "you can have an apple later on because you have been good" or "you cannot have ice cream for dessert at dinner time because you were naughty." The child with little or no language forgets too quickly. The teacher or parent must react on the spot and get her feelings across to the child in perhaps an exaggerated way until he reaches the stage where he can look into the future and link it with the past.

The second special skill is the method of breaking down each task into stages which are small enough for even a very handicapped child to master. Third, the operant-conditioning psychologists know how to use helpful cues and prompting, and then gradually to remove these until the child can do the task without help. Finally, considerable experience is necessary to choose a reward which really means something to the child, and which will make his efforts to learn worthwhile.

Other ways of helping

Many people are trying to find ways of helping these difficult children. To date, there is no one approach that seems to provide the perfect answer.

In recent years in the United States, some new programs have been developed that combine operant conditioning or behavior modification with the training and counseling of parents.

In some areas, professionals have developed a training curriculum in order to teach behavior shaping skills to a small group of parents, teachers, para-professionals and volunteers who then work with the children. This trained group can teach more people, using the original professionals as consultants to the training program. Gradually, the number of "trained" parents, teachers, para-professionals and siblings increases, thus helping many families at a modest cost.

Operant techniques have been used to extinguish socially undesirable behavior, reinforce constructive behavior, build language skills, to teach a child

virtually anything, including academic and vocational skills. The most satisfactory results have been obtained if the parents and teachers work together, both under the guidance of the same advisor.

Most families who have had access to this kind of supportive service have spoken of it as an invaluable aid in enabling them to maintain their child at home more comfortably. They have also noted improvement in their child's overall functioning and adjustment, which has benefitted the whole family.

No one technique, however, is a universal panacea; some families find it hard to accept and use behavior modification with their child, or it may be impossible for the parents to spend the time necessary to carry out the training process. Also, there are some children who do not seem to respond constructively to this kind of approach.

Behavior modification is discussed here because it is now being more widely used in the United States than other methods. There are many other ways of helping autistic children, however, the more traditional educational techniques, special teaching related to each child's specific impairments of function, music and movement, painting and modelling, and involvement in practical, domestic, and outdoor activities, all have their place.

Those who advocate the use of operant conditioning have, sometimes justifiably, been accused of forgetting that human beings, even handicapped ones, are not machines. The wise professional does not limit himself to any one specific approach, but tailors the program to fit the child's and the family's needs.

Usually, a program that combines approaches is most successful and satisfactory for all concerned.

Regardless of the relative merits of the many techniques that are currently being tried, counseling, especially peer counseling, is a most helpful and constructive supportive service that should be available to all families of the handicapped. Parents can effectively help one another learn to deal with the problems with siblings, relatives, neighbors, schools and the like. Such peer counseling, with minimal guidance from a professional, could be provided, quite inexpensively, in every local community.

Picture Courtesy of Vista Hill Foundation

You can help

If you know a family with an autistic child, you may wonder what you can do to help. If you show understanding and acceptance, you will be helping the parents a great deal. If you are a neighbor, you may be disturbed by the child screaming in the night. The parents will know that this causes problems for everyone and this will add to their worries. Your tact and sympathy during this phase may make all the difference.

If you have a relative who has an autistic child, your support will be very welcome, especially if some other members of the family take the attitude that the child "ought to be put away in an institution." The parents should be allowed to make the right decision about the child's future without interference from people who are intolerant and unsympathetic.

It is difficult for the parents of an autistic child to go out together, especially when he is young, because they feel they cannot ask anyone to look after him. Friends, neighbors and relatives can help by offering to babysit. It is easier if you and the child get to know each other first before you have him on your own. You should find out what he understands and how he lets his mother know when he is hungry, thirsty, or wants to use his potty-chair or go to the bathroom. It is useful to know of the things he likes to take to bed with him, whether he has any special fears, and whether he has any favorite songs so that you can sing to him to make him feel safe and comfortable with you. All this sounds like a lot of trouble, but getting to know a handicapped child is rewarding and interesting in itself.

If you live near the family, and especially if you have normal children of your own, you could help a lot by allowing the child to come to your house. His mother will have to come with him at first, so that he can get used to the strange surroundings. Mothers of these children often feel they cannot visit other mothers because their child is so difficult. This is bad for the child too, because he never has the chance to see another house or other children.

Later on, as the child progresses, he may reach the stage when he loves being asked to parties or to go on outings. The trouble is that he does not know what to say or do when he is with other people and he may just sit doing nothing at a lively party. Next time he is not invited because it looks as if he was not enjoying himself. This hurts an autistic child, especially if his brothers and sisters go to parties when he is not asked. He really does enjoy these things, even if he cannot join in actively. If you know a child like this, you can make sure that he is asked to come to the same things as the rest of his family. You can give some explanation to the other people who are there so that they will understand. The child will be very happy if you remember to talk to him every now and again, even if he cannot say much, and if you keep an eye open to make sure that he is not being completely left out.

If you give Christmas and birthday presents to the other children in the family, it is often very difficult to know what to give to the autistic child. *Don't* buy things just because they are suitable for children of his age — they may mean nothing to him at all. It is always best to ask the parents first. There are a number of toys available now that almost seem as if they were made for children with language problems. The Mattel "See and Say" toys are good for the younger ones. These link up the name of musical instruments with their sounds, or the names of animals with the noises they make, and so on. Some autistic children love blocks and other construction toys and simple jig-saw puzzles. The golden rule is to avoid toys and games where the child has to use complicated language and imagination to enjoy them. Don't buy books unless you know that the pictures will interest the child, or that the words are simple enough for him to understand. Pictures should be simple and without fussy details.

Everyone feels sorry for handicapped children. This is very natural, but it can mean that they are protected too much and that everyone gives in to them and spoils them. Most parents find out in the end that this makes their autistic child more difficult than ever. If you know that the parents of an autistic child have laid down certain rules (for example, that he has one piece of candy after dinner and *not* if he screams) then it is very important that you should follow the same rules. When the child is in your house you should never give him something he wants if his mother has said "no." These children are much happier when life is orderly and certain for them, and it makes them worried and upset if grown-ups contradict each other.

Most parents of a handicapped child love him just as much as they do their other normal children. They want other people to see his good points and to accept him for himself. Perhaps the best help you can give to parents in this situation is to show that you really like their handicapped child, that

you are interested in his progress, and that you feel that he has the same value as any other human being. So often parents feel that their child is treated as a "second-class citizen." He may be refused a place in school. The parents may have come in contact with people in official positions who cannot be bothered to take any interest in a backward child. They may have been made miserable by thoughtless comments from people in the street. It is on these occasions that they need the comfort of a good friend who likes their child for his own sake. You can help by giving them an opportunity to talk about their child, listening to the stories they tell about him, and laughing with them at the funny incidents that happen. Humor is a great outlet for emotions for many people, and nothing is more irritating to a parent than talking to someone who takes a hushed and solemn attitude to the handicapped child all of the time. The ability to see the funny side of things can go hand in hand with a basically serious approach to problems, and this combination is a positive and healthy one.

The National Society

Finally, it is important that parents know that a national organization exists, composed of parents, friends, teachers and other concerned professionals, which they may join. This organization is the National Society for Autistic Children, Inc. (NSAC)

In 1980, NSAC began calling itself "NSAC, the National Society for Children and Adults with Autism" to let everyone know it cares for both children and adults with this disorder, since autism does not go away when a child grows up. NSAC is dedicated to the education and welfare of all people with autism and other severe problems of communication and behavior.

NSAC (Pronounced "En-Sack") offers support for the families of such children and adults by giving them access to the most up-to-date knowledge available regarding education, treatment and management of children; and housing, prevocational and vocational training for adults.

As this edition goes to press, there are 161 chapters and state societies of NSAC, at least one in every state of the union. Aside from disseminating valuable information about services that are available in various regions, these chapters offer the strength, support and friendship of other families who face or have faced similar problems with this kind of child. The existence of an active chapter of NSAC in a community is one of the best ways known to insure that appropriate local programs for people with autism are provided.

The National Society publishes a newsletter, the *Advocate*, that is distributed six times a year. NSAC also provides material to members either free or at a nominal cost.

NSAC is a member of the National Health Council, and spends most of its resources educating parents, professionals and the general public about autism. It supports research aimed at identifying the causes of autism and finding better ways to deal with the problems of autistic children and adults. For example, because of the Society's work, the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), one of the National Institutes of Health, has established a Research Section on Autism and Behavioral Disorders. This new section will focus the energy of many scientific investigators on the problems of autism.

The Society does not directly subsidize schools or other training programs, but its chapters do promote appropriate educational, vocational and community living arrangements for people with autism. Occasionally, a chapter will start such a program, but will then turn it over to a public or private agency. NSAC believes that chapters are more effective when they can encourage agencies — whose business it is to provide services — to provide for people with autism. In other words, NSAC chapters advocate direct services, rather than provide them.

Another way in which NSAC helps is through its annual meeting and conference held in a different state each year, around the end of June or the first of July. These national conferences bring

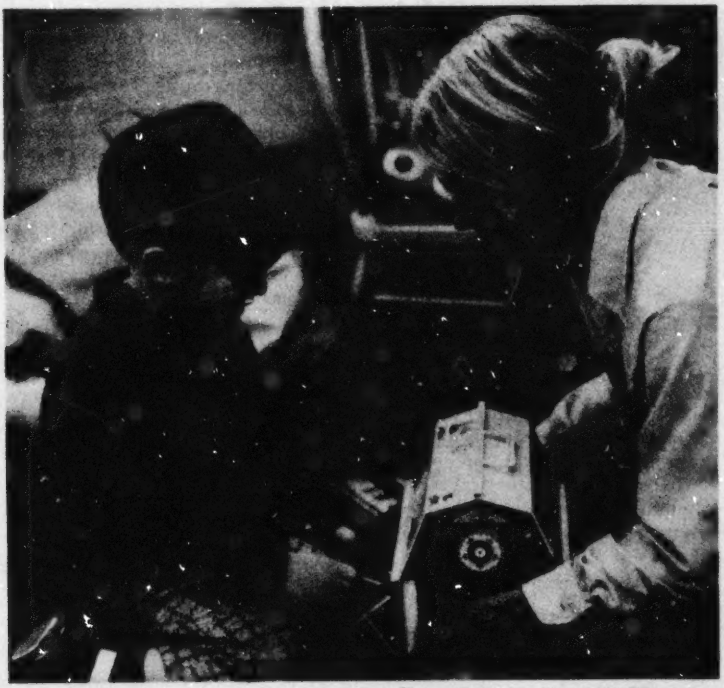
together parents and professionals from all over the country, and provide them with the latest information available on education, management and treatment of autistic children and adults. The *Proceedings* of these conferences are available from the NSAC national office.

For More Information

Contact: NSAC, 1234 Massachusetts Avenue, N.W., Suite 1017, Washington, D.C. 20005. Phone: (202) 783-0125 for the location of NSAC chapters, information on NSAC conferences, national and regional and other information on the Society.

Contact: The NSAC Information and Referral Service, 1234 Massachusetts Avenue, N.W., Suite 1017, Washington, D.C. 20005. Phone (202) 783-0125 for suggested reading material, books, articles, etc.; lists of facilities serving people with autism, summer camps, group homes, respite care programs, etc. The NSAC-IRS provides personalized information to parents and others with specific questions.

In the fall of 1972, a meeting was held in Christchurch, England, to determine whether or not sufficient interest existed to warrant the formation of an International Society for Autistic Children. Many countries from different parts of the world were represented at this meeting, including the United States of America. It appears that there is much interest in this project, and the organization of such an international society is now officially underway. It is hoped that international meetings can be held every few years. The British Society for Autistic Children, the parent organization of all the many national societies for autistic children throughout the world, is the organizing force behind this effort. Its primary function will be to gather and disseminate information about autism from and to its membership of national societies. This should greatly enhance the scope of information available in all countries on early childhood autism. More information about the International Society for Autistic Children is available from the International Society for Autistic Children, 1a, Golders Green Road, London, N.W. 11, England.



Picture Courtesy of Vista Hill Foundation

Services for Children and Adults with Autism

Autistic children need skilled teaching, but unfortunately there are far more children than there are school placements.

Adults with autism need places to live and work, but their needs have been poorly understood; and few group homes, apartments and job placements have been provided.

Most states, at the urging of the federal government, NSAC chapters, the courts and improved federal laws, are beginning to provide structured educational services, community living arrangements and habilitative or vocational training for children and adults with autism and other handicapping conditions.

Since the 1970s, it has been government policy to educate all handicapped children in public schools and to provide places in the community for handicapped adults to live and work, rather than segregating them from others in special schools, "hospitals," centers for the retarded or mentally ill or in custodial institutions.

Such provision of "community based" services has been particularly slow in coming for people with autism. At the present time, few communities or states offer appropriate educational programs at the local level for autistic children, even though a "free, appropriate public education" is mandated under Public Law 94-142, the "Education For All Handicapped Act."

Often when services are available, they can service only a fraction of those in need. Moreover, the quality of available programs is frequently poor, offering little more than custodial care; with slight or no effort being made to provide education or training to improve functioning. Occasionally, such "babysitting" programs serve the purpose of allowing families much-needed daily respite.

Comparison studies in the United States have shown that these programs are usually more expensive than well-structured educational programs. Studies also show that people with autism make the greatest sustained improvement when they are provided an appropriate educational setting, which most often includes some form of behavior modification. It seems obvious, then, that new programs must be established, existing ones expanded, and their program structures altered to meet the needs of all these children while making the best use of available funds. One of the best tools to accomplish this is the "Individualized Education Program" (IEP) requirement in P.L. 94-142. Professionals and responsible agencies should not be content unless they are providing the best possible program, and serving all of the children entrusted to their care. Parents should not be content until their child's IEP addresses his every educational need.

Parents of these children must be very persistent in their efforts to obtain appropriate services for their special child. Their quest will probably involve working with their local school principal and teacher, or could lead to making the need for services known to their local, county and/or state school board. If faulty state legislation is to blame for lack of educational services, then resolving the situation must surely involve a change in these state laws, which would entail working with the state legislature and governor's office. This is where the strength and influence of an active NSAC chapter can be of invaluable aid, and the NSAC National Office can provide technical assistance.

Sometimes, for various reasons, autistic children cannot live at home. Special residential schools may solve the problem, but there are very few places available for autistic children, and these are very expensive. Some states provide payment of tuition so that such children can attend private residential schools when necessary. This is a requirement of P.L. 94-142. Many of these children, when responsible agencies fail to provide as required by Federal Law, may be sent to hospitals for people who are mentally sub-normal or mentally ill. These "warehouses for humans" are often very large institutions which are not only understaffed, but usually lack any well-organized active treatment programs for their patients. As a rule, children in such institutions do not have access to appropriate school programs taught by credentialed teachers; they are fortunate to be involved in any kind of daily activity that takes them from their ward. Autistic children do poorly in such hospitals because they do not have the special attention and teaching they need. Today, people working with handicapped children feel that small homes run as families with special schools close by are much better than these large institutions.

When autistic children reach adolescence, they still behave in a very immature way, and they still need teaching. They also need training so that they can learn to do some kind of work when they grow

up. At the moment it is almost impossible to find places where such education and training are provided for these young people. Such educational and vocational training must be provided, however, if any of these individuals are to become even partially self-sufficient as adults.

Autism causes handicaps all through life. Adults who have been autistic as children may sometimes be able to earn their living at an ordinary job, but most will need sheltered work. Again, there are very few job placements available at this time, although sheltered workshops would be very helpful for all kinds of handicapped people.

Group homes and apartments are needed for autistic adults who no longer have a family home where they can live. Very little has been done as yet to provide services of this kind in the United States, though model programs exist. The manner in which a society treats its handicapped citizens is one index by which it is judged by other nations and history. How would the United States of America measure up, using such a yardstick of values? Obviously, we still have a long way to go.

WE INVITE YOU TO HELP NSAC IN ITS WORK FOR CHILDREN AND ADULTS WITH AUTISM

NSAC is a non-profit, tax exempt association of parents, professionals and others dedicated to the education and welfare of children and adults with autism and related disorders of communication and behavior.

It is governed by an elected Board of Directors, and carries out its work through the National Office in Washington, DC, and its 157 chapters and state societies across the nation.

The Internal Revenue Service has determined that NSAC meets the criteria described in Section 501 (c) (3) of the Internal Revenue Code, and the contributions made to the Society are deductible by the donor.

Here are ways you can assist:

- Contribute to the general programs of the Society. Most of our assistance is in this form. Any amount will be gratefully acknowledged.
- If you represent a corporation, include NSAC in your program of corporate giving. Corporate gifts are increasingly necessary as government support dwindles.
- Make designated contributions. You may consider Society publications, the Information and Referral Service, the NSAC Student Intern Program, the Legal Services Fund, the Autism Library Project, the NSAC Research Fund, the National Affairs Committee, or other Society activities and projects.
- Make a Memorial Contribution to honor the memory of a loved one or friend. If you are in charge of arrangements, you may wish to request that contributions be made to NSAC in lieu of flowers.
- Join NSAC as a Contributing ($45), Supporting ($65), Sponsoring ($300), Patron ($1,500), or Life ($3,000) member.
- Include NSAC in your will. Consult your attorney or financial advisor for specifics. While state laws vary, a bequest may be as simple as the following statements: "I give and bequeath to the National Society for Autistic Children, Inc. (our legal name), or its successor or successors, the sum of _____ (or describe property) to be used for the purposes of the said corporation at the direction of its Board of Directors."
- Make NSAC the beneficiary of a portion or all of your life insurance. Consider the advantages to the donor as well as the benefactor — including tax deductible premiums. Such a gift may be through purchase of a new policy or by altering the beneficiary of current policies.
- Make an Annual Pledge. Simply send the following to the NSAC National Office: "I (we) pledge to contribute _____ dollars to the National Society for Autistic Children each year, and will expect regular notification when this pledge is due."

Remember that NSAC is the only national organization dedicated to alleviating the heartbreaking effects of autism. Your help offers hope to a child in need.

Send all gifts to:

NSAC, The National Society for Children
and Adults with Autism
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005-4599

We will be happy to discuss any proposed contribution or bequest at your convenience.

Thank You,

Norman A. Fuller

Norman A. Fuller, Ph.D.
Executive Director

Definition of Autism

AUTISM is a severely incapacitating lifelong developmental disability which typically appears during the first three years of life. It occurs in approximately five out of every 10,000 births* and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism.

The symptoms are caused by physical disorders of the brain. They include:

(1) Disturbances in the rate of appearance of physical, social and language skills.

(2) Abnormal responses to sensation. Any one or a combination of sight, hearing, touch, pain, balance, smell, taste, and the way a child holds his body are affected.

(3) Speech and language are absent or delayed while specific thinking capabilities may be present.

(4) Abnormal ways of relating to people, objects and events.

Autism occurs by itself or in association with other disorders which affect the function of the brain such as viral infections, metabolic disturbances, and epilepsy.

On IQ testing, approximately 60% have scores below 50, 20% between 50 and 75, and only 20% greater than 70. Most show wide variations of performance on different tests and at different times.

Autistic people live a normal life span. Since symptoms change, and some may disappear with age, periodic re-evaluations are necessary to respond to changing needs.

The severe form of the syndrome may inclue extreme self-injurious, repetitive, highly unusual and aggressive behaviors.

Special educational programs using behavioral methods have proved to be the most helpful treatment.

*For educational planning, the incidence figure is about 15 in 10,000 births. This includes children with autism and related communication handicaps who need similar educational programming.

Lorna Wing, M.D., 1979

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membership application

(Please Print)

_____
(Name)

_____
(Address)

_____
(City) (State)

_____
(Zip) (Phone)

Chapter Affiliation

_____
(If none, indicate "at large" membership)

Referred for membership by:

_____
(Chapter or Individual)

Applying for membership as:

- ☐ Full time student — $7.50
- ☐ Regular — $15 per individual
- ☐ Family — husband & wife — $22.50
- ☐ Contributing — $45
- ☐ Supporting — $65
- ☐ Sponsoring — $300
- ☐ Patron — $1,500
- ☐ Life — $3,000

Please circle applicable category(ies):
parent grandparent relative friend teacher
physician psychiatrist psychologist researcher
other (professional, etc.) _____

Note: Subscription to the Advocate is included in your annual membership dues for any category above.

FOREIGN MEMBERSHIPS, EXCEPT CANADA, Add $3.00
Local chapter and state society dues are extra.

YOUR CONTRIBUTION IS TAX DEDUCTIBLE

Detach and mail in envelope to:

Headquarters Office
NSAC, The National Society for Children and Adults with Autism
1234 Massachusetts Ave., N.W.
Washington, D.C. 20005-4599
(202) 783-0125